

108TH CONGRESS
1ST SESSION

H. R. 1138

To amend the Public Health Service Act to provide for Alzheimer's disease research and demonstration grants.

IN THE HOUSE OF REPRESENTATIVES

MARCH 6, 2003

Mr. MARKEY (for himself and Mr. SMITH of New Jersey) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend the Public Health Service Act to provide for Alzheimer's disease research and demonstration grants.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Alzheimer's Disease
5 Research, Prevention, and Care Act of 2003”.

6 **SEC. 2. FINDINGS.**

7 Congress makes the following findings:

8 (1) Alzheimer's disease is a disorder that de-
9 stroys cells in the brain. The disease is the leading
10 cause of dementia, a condition that involves gradual

1 memory loss, decline in the ability to perform rou-
2 tine tasks, disorientation, difficulty in learning, loss
3 of language skills, impairment of judgment, and per-
4 sonality changes. As the disease progresses, people
5 with Alzheimer's disease become unable to care for
6 themselves. The loss of brain cells eventually leads
7 to the failure of other systems in the body.

8 (2) In the United States, 4,000,000 people have
9 Alzheimer's disease and 19,000,000 people say that
10 they have a family member with the disease. By
11 2050, 14,000,000 people in the United States will
12 have Alzheimer's disease unless science finds a way
13 to prevent or cure the disease.

14 (3) One in 10 people over the age of 65, and
15 nearly half of those over the age of 85 have Alz-
16 heimer's disease. Younger people also get the dis-
17 ease.

18 (4) The Alzheimer's disease process may begin
19 in the brain as many as 20 years before the symp-
20 toms of Alzheimer's disease appear. A person will
21 live an average of 8 years and as many as 20 once
22 the symptoms of Alzheimer's disease appear.

23 (5) The average lifetime cost of Alzheimer's dis-
24 ease, per person, is \$174,000.

1 (6) In 2000, medicare alone spent
2 \$31,900,000,000 for the care of individuals with
3 Alzheimer's disease and this amount is projected to
4 increase to \$49,300,000,000 in 2010.

5 (7) Forty-nine percent of medicare beneficiaries
6 who have Alzheimer's disease also receive medicaid.
7 Of the total population dually eligible for medicare
8 and medicaid, 22 percent have Alzheimer's disease.

9 (8) Seven in 10 people with Alzheimer's disease
10 live at home. While almost 75 percent of home care
11 is provided by family and friends, the average an-
12 nual cost of paid care for people with Alzheimer's
13 disease at home is \$19,000.

14 (9) Nearly 60 percent of all nursing home resi-
15 dents have Alzheimer's disease or another dementia.
16 The average annual cost of Alzheimer's disease nurs-
17 ing home care is nearly \$64,000. Medicaid pays
18 nearly half of the total nursing home bill and helps
19 2 out of 3 residents pay for their care. Medicaid ex-
20 penditures for nursing home care for people with
21 Alzheimer's disease are estimated to increase from
22 \$18,200,000,000 in 2000 to \$33,000,000,000 in
23 2010.

24 (10) In fiscal year 2002, the Federal Govern-
25 ment spent an estimated \$598,900,000 on Alz-

1 heimer's disease research. If our Nation achieves its
2 research goals (preventing the onset of Alzheimer's
3 disease in those at risk and treating and delaying
4 progression of the disease in those who have symp-
5 toms), the projected number of cases of Alzheimer's
6 disease can be reduced by more than one-third by
7 the middle of the century and the number of baby
8 boomers with moderate to severe Alzheimer's disease
9 can be reduced by 60 percent.

10 (11) A study commissioned by the United Hos-
11 pital Fund estimated that the annual value of this
12 informal care system is \$257,000,000,000. Family
13 caregiving comes at enormous physical, emotional,
14 and financial sacrifice, putting the whole system at
15 risk.

16 (12) One in 8 Alzheimer's disease caregivers be-
17 comes ill or injured as a direct result of caregiving.
18 One in 3 uses medication for problems related to
19 caregiving. Older caregivers are 3 times more likely
20 to become clinically depressed than others in their
21 age group.

22 (13) Elderly spouses strained by caregiving are
23 63 percent more likely to die during a given 4-year
24 period than other spouses their age.

1 (14) Three of 4 caregivers are women. One in
2 3 has children or grandchildren under the age of 18
3 living at home. Caregiving leaves them less time for
4 other family members and they are much more likely
5 to report family conflicts because of their caregiving
6 role.

7 (15) Most Alzheimer’s disease caregivers work
8 outside the home before beginning their caregiving
9 careers, but caregiving forces them to miss work, cut
10 back to part-time, take less demanding jobs, choose
11 early retirement, or give up work altogether. As a
12 result, in 2002, Alzheimer’s disease cost American
13 business an estimated \$36,500,000,000 in lost pro-
14 ductivity, as well as an additional \$24,600,000,000
15 in business contributions to the total cost of care.

16 **SEC. 3. PRIORITY TO ALZHEIMER’S DISEASE RESEARCH.**

17 Section 443 of the Public Health Service Act (42
18 U.S.C. 285e) is amended—

19 (1) by striking “The general” and inserting
20 “(a) IN GENERAL.—The general”; and

21 (2) by adding at the end the following:

22 “(b) PRIORITIES.—The Director of the Institute
23 shall, in expending amounts appropriated under this sub-
24 part, give priority to conducting and supporting Alz-
25 heimer’s disease research.”.

1 **SEC. 4. ALZHEIMER'S DISEASE PREVENTION INITIATIVE.**

2 Section 444 of the Public Health Service Act (42
3 U.S.C. 285e–1) is amended—

4 (1) in subsection (d), by inserting “and train-
5 ing” after “conduct research”; and

6 (2) by adding at the end the following:

7 “(e) The Director of the National Institutes of
8 Health shall, in collaboration with the Director of the In-
9 stitute, the directors of other relevant institutes, and with
10 volunteer organizations and other stakeholders, undertake
11 an Alzheimer’s Disease Prevention Initiative to—

12 “(1) accelerate the discovery of new risk and
13 protective factors for Alzheimer’s disease;

14 “(2) rapidly identify candidate diagnostics,
15 therapies, or preventive interventions or agents for
16 clinical investigations and trials relating to Alz-
17 heimer’s disease;

18 “(3) support or undertake such investigations
19 and trials; and

20 “(4) implement effective prevention and treat-
21 ment strategies, including strategies to improve pa-
22 tient care and alleviate caregiver burdens relating to
23 Alzheimer’s disease.”.

1 **SEC. 5. ALZHEIMER'S DISEASE CLINICAL RESEARCH.**

2 (a) CLINICAL RESEARCH.—Section 445F of the Pub-
3 lic Health Service Act (42 U.S.C. 285e–8) is amended to
4 read as follows:

5 **“SEC. 445F. ALZHEIMER'S DISEASE CLINICAL RESEARCH.**

6 “(a) IN GENERAL.—The Director of the Institute,
7 pursuant to subsections (d) and (e) of section 444, shall
8 conduct and support cooperative clinical research regard-
9 ing Alzheimer's disease. Such research shall include—

10 “(1) investigating therapies, interventions, and
11 agents to detect, treat, slow the progression of, or
12 prevent Alzheimer's disease;

13 “(2) enhancing the national infrastructure for
14 the conduct of clinical trials;

15 “(3) developing and testing novel approaches to
16 the design and analysis of such trials;

17 “(4) facilitating the enrollment of patients for
18 such trials, including patients from diverse popu-
19 lations;

20 “(5) developing improved diagnostics and
21 means of patient assessment for Alzheimer's disease;
22 and

23 “(6) as determined appropriate by the Director
24 of the Institute, the Alzheimer's Disease Centers
25 and Alzheimer's Disease Research Centers estab-
26 lished under section 445.

1 “(b) EARLY DIAGNOSIS AND DETECTION RE-
2 SEARCH.—

3 “(1) IN GENERAL.—The Director of the Insti-
4 tute, in consultation with the directors of other rel-
5 evant institutes and centers of the National Insti-
6 tutes of Health, shall conduct, or make grants for
7 the conduct of, research related to the early detec-
8 tion and diagnosis of Alzheimer’s disease and of
9 mild cognitive impairment or other potential precur-
10 sors to Alzheimer’s disease.

11 “(2) EVALUATION.—The research described in
12 paragraph (1) may include the evaluation of diag-
13 nostic tests and imaging techniques.

14 “(c) VASCULAR DISEASE.—The Director of the Insti-
15 tute, in consultation with the directors of other relevant
16 institutes and centers of the National Institutes of Health,
17 shall, conduct or make grants for the conduct of, research
18 related to the relationship of vascular disease and Alz-
19 heimer’s disease, including clinical trials to determine
20 whether drugs developed to prevent cerebrovascular dis-
21 ease can prevent the onset or progression of Alzheimer’s
22 disease.

23 “(d) NATIONAL ALZHEIMER’S COORDINATING CEN-
24 TER.—The Director of the Institute may establish a Na-
25 tional Alzheimer’s Coordinating Center to facilitate col-

1 laborative research among the Alzheimer’s Disease Cen-
 2 ters and Alzheimer’s Disease Research Centers established
 3 under section 445.”.

4 (b) ALZHEIMER’S DISEASE CENTERS.—Section
 5 445(a)(1) of the Public Health Service Act (42 U.S.C.
 6 285e–2(a)(1)) is amended by inserting “, and outcome
 7 measures and disease management” after “treatment
 8 methods”.

9 **SEC. 6. RESEARCH ON ALZHEIMER’S DISEASE CAREGIVING.**

10 Section 445C of the Public Health Service Act (42
 11 U.S.C. 285e–5) is amended—

12 (1) by striking “SEC. 445C. (a)” and inserting
 13 the following:

14 **“SEC. 445C. RESEARCH ON ALZHEIMER’S DISEASE SERV-**
 15 **ICES AND CAREGIVING.**

16 “(a) SERVICES RESEARCH.—”;

17 (2) by striking subsections (b), (c), and (e);

18 (3) by inserting after subsection (a) the fol-
 19 lowing:

20 “(b) INTERVENTIONS RESEARCH.—The Director
 21 shall, in collaboration with the directors of the other rel-
 22 evant institutes and centers of the National Institutes of
 23 Health, conduct, or make grants for the conduct of, clin-
 24 ical, social, and behavioral research related to interven-
 25 tions designed to help caregivers of patients with Alz-

1 heimer’s disease and related disorders and improve patient
2 outcomes.”; and

3 (4) in subsection (d) by striking “(d) the Direc-
4 tor” and inserting “(c) MODEL CURRICULA AND
5 TECHNIQUES.—The Director”.

6 **SEC. 7. AUTHORIZATION OF APPROPRIATIONS.**

7 (a) IN GENERAL.—Section 445J of the Public Health
8 Service Act (42 U.S.C. 285e–11) is amended by striking
9 “\$500,000,000 for fiscal year 1994, and such sums as
10 may be necessary for each of the fiscal years 1995 and
11 1996.” and inserting “\$1,100,000,000 for fiscal year
12 2004, \$1,200,000,000 for fiscal year 2005,
13 \$1,300,000,000 for fiscal year 2006, \$1,400,000,000 for
14 fiscal year 2007, and \$1,500,000,000 for fiscal year
15 2008.”.

16 (b) AGING PROCESS REGARDING WOMEN.—Section
17 445H(b) of the Public Health Service Act (42 U.S.C.
18 285e–10(b)) is amended by striking “2003” and inserting
19 “2008”.

20 (c) CLINICAL RESEARCH AND TRAINING AWARDS.—
21 Section 445I(d) of the Public Health Service Act (42
22 U.S.C. 285e–10a(d)) is amended by striking “2005” and
23 inserting “2008”.

1 **SEC. 8. ALZHEIMER'S DISEASE DEMONSTRATION GRANTS.**

2 Section 398B(e) of the Public Health Service Act (42
3 U.S.C. 280c-5(e)) is amended—

4 (1) by striking “and such” and inserting
5 “such”; and

6 (2) by inserting before the period “,
7 \$20,000,000 for fiscal year 2004, and such sums as
8 may be necessary for each of the fiscal years 2005
9 through 2008”.

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